

## Chapter 11

# Identification and Treatment of Attention Deficit-Hyperactivity Disorder: A Lifespan Perspective

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## Introduction

Attention deficit-hyperactivity disorder (ADHD) is a lifelong disorder best understood within a developmental framework (Barkley, 1998a; Teeter, 1998; Weiss, 1999; Weiss and Hechtman, 1993). ADHD affects approximately five to seven percent of school-age children across the United States (Bararesi et al., 2002; Leibson et al., 2001), between two and six percent of adolescents (Murphy and Barkley, 1996a), and two percent of adults (Hunt, 1997). Up to 80 percent of individuals diagnosed during childhood continue to have ADHD during adolescence (Barkley, et al., 1990), and up to 60 percent of adolescents exhibit ADHD symptoms into adulthood

(Barkley, 1998a; Ingram, et al., 1999; Weiss, et al., 1985). Persons with persistent ADHD have more severe symptoms during childhood and experience more adversity factors, such as family stress and dysfunction (Cuffe et al., 2001).

ADHD is a controversial disorder, and the psychosocial, behavioral problems associated with it are frequently misunderstood (Teeter Ellison, 2002a). Although research evidence documents compromised neurological and genetic substrates, multiple interacting systems are most likely involved. ADHD is best understood within a developmental systems perspective, in which compromised neural systems affect the adaptive functioning of the individual and the family, home, school/work,

and community environment contribute to the manifestation of ADHD and the spectrum of coexisting disorders that frequently accompany it (Biederman, et al., 1996; Ingram et al., 1999; Teeter, 1998; Teeter Ellison, 2002b).

Problems in behavioral inhibition or self-control appear related to dysfunction in frontal-striatal networks, while other brain regions (basal ganglia, including the caudate nucleus and cerebellum) have also been implicated (Casey et al., 1997; Castellanos et al., 1994; Semrud-Clikeman et al., 2000; Tan-nock, 1998). Structural neuroimaging and select functional studies of youths with ADHD have found that certain brain regions on average are smaller in size, have less electrical activity, and are less responsive to stimulation. Recently, a 10-year study conducted by scientists at the National Institute of Mental Health (NIMH) investigated brain volume abnormalities in 152 children and adolescents between 5 and 18 years of age with ADHD and contrasted them with 139 non-ADHD controls. Repeated MRI scans on 60 percent of all participants showed on average a 3 percent smaller brain volume for those with ADHD (Castellanos et al., 2002). Smaller brain regions were correlated with symptom severity (i.e., Clinical Global Impressions ratings, parent-rated child behavior checklists). Furthermore, the “strikingly smaller” white matter volume in children with ADHD did not appear related to stimulant medication use. While this study is intriguing, future research should focus on nonreferred children at earlier ages.

The evidence of genetic transmission of ADHD, primarily involving the dopamine systems that innervate frontal-striatal regions, is also compelling (Barkley, 1998a). Studies estimate that 60 to 91 percent of deficits in behavioral inhibition and inattention—particularly more extreme forms—are genetically transmitted (Faraone, 1996; Sherman, et al., 1997). Research investigating the manner in which the environment interacts with subtle brain anomalies and genetic differences is ongoing. Varying degrees of risk factors, such as parental psychopathology, inadequate parenting practices, and other psychosocial stressors, including poverty and family dysfunction, complicate ADHD features (Biederman, et al., 1996).

Core symptoms of hyperactivity, impulsivity, and inattention comprise the major characteristics of the disorder, with new conceptualizations emphasizing motivational, behavioral, and emotional self-regulation deficits (Barkley, 1997, 1998a). Symptoms of ADHD typically first appear in childhood and, for a majority of individuals, persist into young

adulthood (Barkley, 1998a; Ingram et al., 1999). The symptoms of ADHD have pervasive consequences that vary depending on life challenges of each developmental stage. Table 1 presents a summary of recent findings from the quantitative, empirical literature. Children with ADHD are at risk for (1) interpersonal problems (i.e., peer rejection, parent-child conflict); (2) difficulties in educational functioning (i.e., learning disabilities, grade retention, low graduation rates, low grade point average); and (3) comorbidity with other psychiatric illnesses. Consequences in adolescence and early adulthood include lowered educational attainment; involvement in the criminal justice system; and patterns of risky drinking, driving, and sexual behaviors. By adulthood, instability and difficulty fulfilling work, marital, and parental roles are common.

ADHD has additional social consequences: children, adolescents, and adults diagnosed with ADHD are consumers of costly mental health services (Leibson et al., 2001). Recent data collected by the Center for Mental Health Services (CMHS) demonstrates the prevalence of ADHD in the mental health service sector. This nationally representative sample survey of about 8,000 children and adolescents (0 to 17 years old) served in more than 1,600 inpatient, outpatient, and residential care facilities in 1997—according to the 1997 Client/Patient Sample Survey (CPSS)—shows that nearly 14 percent of the youth are assigned a diagnosis of ADHD (for study description, see chapter 10 of this volume). The study includes youths who were seen at some type of community mental health facility, whether a clinic, hospital, community center, or social service agency. This means that estimates of youths with ADHD receiving help for their psychiatric problems are conservative. They do not include those youth who consulted with individual mental health therapists in private practice or those who were treated by medical doctors in primary care settings. Families of children with ADHD are more likely to have chronic family conflict, decreased family cohesion, increased marital conflict, high rates of divorce, and less marital satisfaction (Biederman et al., 1995; Murphy and Barkley, 1996a). These stress factors often compel parents to seek mental health services for their children with ADHD.

## **Identification, Assessment, and Diagnosis**

It can be difficult to identify ADHD accurately because of the complexity of its clinical, psychoso-

Table 1. Select summary of characteristics and associated problems of ADHD through the lifespan

Authors	Major research findings
<b>Early and Middle Childhood (6–12 years)</b>	
Barkley (1998a); Barkley et al. (1990)	<ul style="list-style-type: none"> <li>• 40–60% develop ODD</li> <li>• 25–40% likely to show signs of CD</li> <li>• 25% fight with peers</li> <li>• 60–80% placed on a trial of stimulants</li> <li>• 50% or more have had individual or family therapy</li> <li>• 30–45% formal special education</li> </ul>
Barkley (1998a)	<ul style="list-style-type: none"> <li>• Mild cognitive impairments (i.e., working memory, planning, goal-directedness)</li> <li>• Deficient academic achievement</li> <li>• Delayed motor coordination (52%)</li> <li>• Adaptive functioning (10–30 points below normal)</li> <li>• Increased risk for accidental injuries</li> <li>• Delayed onset of language or impaired speech</li> <li>• Deficient rule-governed behavior</li> <li>• Greater variability of task performance</li> <li>• Poor self-regulation of emotion and low frustration tolerance</li> <li>• Disruptive classroom behavior</li> </ul>
<b>Late Childhood and Adolescence</b>	
Bagwell et al. (2001)	<p>Persistent ADHD compared with non-ADHD youth (13–18 years of age)</p> <ul style="list-style-type: none"> <li>• Parents report: Fewer friends, higher rates of peer rejection, 11% of ADHD teens have no close friends (vs. 1% non-ADHD group)</li> <li>• Teachers report: greater peer rejection for ADHD teens</li> <li>• Presence of childhood aggression lowered self-reports of social competence, peer acceptance; parents report fewer close friendships for ADHD teens</li> <li>• Presence of CD: self reports more friends use substances, friends are engaged in less conventional activities; parents report high rates of disapproval of friends (64%) versus ADHD non-CD (38%) and 28% of non-ADHD group</li> </ul>
Barkley et al. (1990); Fischer et al. (1990)	<p>Milwaukee study: 8-year followup of boys with ADHD (12–20 years of age)</p> <ul style="list-style-type: none"> <li>• 71.5% continue to meet criteria for ADHD</li> <li>• 60% diagnosed with ODD</li> <li>• 43% diagnosed with CD</li> <li>• 10% dropped out of school vs. 0% of controls</li> <li>• 29.3% failed a grade vs. 10% of controls</li> <li>• 46.3% suspended vs. 15.2% of controls</li> <li>• 10.6% expelled vs. 1.5% of controls</li> <li>• ADHD + CD increases risk for expulsion (21.7%), suspension (67.4%), and dropping out (13%)</li> <li>• Stolen without confrontation (49.6%), firesetting (27.6%)</li> <li>• 80.5% methylphenidate (36 mos.), 3.3% d-amphetamine (1.1 mos.), 19.5% pemoline (2.6 mos.), 1.6% tranquilizer (0.1 mos.), 14.6% other psychotropic drugs (0.4 mos.)<sup>1</sup></li> <li>• 63.4% psychotherapy (16.3 mos.), 49.6% family therapy (7.2 mos.), 32.5% in learning disability classes (65.5 mos.), 35.8% in behavior disorder classes (59.1 mos.), 16.3% speech classes (40.2 mos.)<sup>2</sup></li> </ul>

Table 1. Select summary of characteristics and associated problems of ADHD through the lifespan (Continued)

<b>Authors</b>	<b>Major research findings</b>
Biederman et al. (1996)	4-year followup of boys with ADHD (6–17 years of age) <ul style="list-style-type: none"> <li>• 85% continue to have ADHD</li> <li>• 15% remitted (half in childhood, half in adolescence)</li> </ul>
Biederman et al. (1998)	Adolescent and childhood ADHD (6–17 years of age) <ul style="list-style-type: none"> <li>• Adolescents higher rates of family history of ADHD</li> <li>• Similar number of DSM-III-R symptoms of ADHD at baseline (8.9 for children and 9.0 for adolescents) for both children and teens with ADHD</li> <li>• Similar number of DSM-III-R symptoms of ADHD at 4-year followup for both children and teens with ADHD</li> <li>• Rates of comorbidity for children versus adolescents with ADHD               <ul style="list-style-type: none"> <li>42% vs. 25% conduct disorder</li> <li>54% vs. 44% major depression</li> <li>46% vs. 35% multiple anxiety</li> <li>46% vs. 33% oppositional defiant</li> <li>22% vs. 28% bipolar disorder</li> <li>3% vs. 40% substance abuse<sup>2</sup></li> </ul> </li> </ul>
Satterfield and Schell (1997)	Adolescents with ADHD + oppositional and conduct disorders (ODD/CD) vs. ADHD with no ODD/CD at greater risk for: <ul style="list-style-type: none"> <li>• Increased arrests; 50% of ADHD had a felony arrest</li> <li>• Minor antisocial behaviors including aggressiveness and defiance (indicators of CD)</li> </ul>
<b>Adulthood</b>	
Barkley and Gordon (2002)	Milwaukee followup study; ADHD vs. control group (mean age 21–22 years) <ul style="list-style-type: none"> <li>• Begin sexual activity at earlier age (15 vs. 16 years)</li> <li>• More sexual partners (19 vs. 7)</li> <li>• Teenage pregnancy (38% vs. 4%)</li> <li>• Contracted sexually transmitted disease (17% vs. 4%)</li> </ul>
Fischer et al. (2002)	Milwaukee followup study: 13-year followup study of ADHD children into early adulthood (mean age 21–22 years) <ul style="list-style-type: none"> <li>• Higher risk for nondrug psychiatric disorders vs. controls (59% vs. 36%)</li> <li>• More personality disorders (passive-aggressive, histrionic, borderline, antisocial) and major depression than controls</li> <li>• Childhood hyperactivity increases later risk for ASPD</li> <li>• Severity of childhood conduct problems + ADHD increases risk for ASPD</li> <li>• High levels of both hyperactivity with conduct problems have greater antisocial adult outcomes than either disorder alone</li> </ul>
Ingram et al. (1999)	Longitudinal study of children with ADHD into adulthood <ul style="list-style-type: none"> <li>• 70–80% meet diagnostic criteria for ADHD in adolescence</li> <li>• 60% continue to exhibit various symptoms in adulthood (more social, emotional, and impulsive problems than controls) but fewer meet diagnostic criteria</li> <li>• Fewer than 10% are grossly disturbed, requiring psychiatric hospitalization or prison</li> <li>• 30–40% show fairly normal functioning</li> </ul>

Table 1. Select summary of characteristics and associated problems of ADHD through the lifespan (Continued)

Authors	Major research findings
Barkley and Gordon (2002) Murphy and Barkley (1996a, 1996b); Murphy, Barkley, and Bush (2001)	<p>Clinic-referred adults compared to community controls</p> <ul style="list-style-type: none"> <li>• Fired more often (53% vs. 31% controls)</li> <li>• Quit jobs more frequently (48% vs. 16% controls)</li> <li>• Chronic employment difficulties (77% vs. 57% controls)</li> <li>• Higher scores on self-report measures of interpersonal sensitivity and hostility</li> <li>• Higher rates of divorce and remarriage, less marital satisfaction</li> </ul>

<sup>1</sup> Numbers in parentheses represent duration of treatment.

<sup>2</sup> Rates for children presented before adolescent rates. Control group had 33 percent substance abuse or dependence.

Note: ASPD = antisocial personality disorder; CD = conduct disorders; ODD = oppositional defiant disorder.

cial, and behavioral symptoms. According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) (APA, 1994), three subtypes can be identified: attention disorder predominantly inattentive type (ADD/PI), attention deficit/hyperactivity disorder predominantly hyperactive-impulsive type (AD/PHI), and attention deficit/hyperactivity disorder combined type (AD/C). ADD/PI often includes a cognitive disability (i.e., “spacey,” day dreamy, sluggish, and easily confused) resulting from slow information processing and poorly focused or selective attention, whereas inattention in individuals with ADD/PHI and ADD/C usually reflects problems with sustained attention and distractibility. ADHD subtypes appear to respond differently to medication, in that ADD/PI is somewhat less responsive to stimulant medications than ADD/PHI and ADD/C types (Milich, et al., 2002). Recently the DSM-IV subtypes have been challenged, and some argue that ADHD subtypes represent separate disorders. “Thus, not only do these two disorders have nothing in common, but in many ways appear to fall on opposite ends of a continuum—disinhibited versus inhibited, overactive versus hypoactive, externalizing versus internalizing, energetic versus sluggish” (Milich et al., 2002). Although this controversy is not yet resolved, the features of “inconsistent alertness and orientation” characterized by slow memory retrieval, low alertness, slow information processing, and problems with orientation are common in children ADD/PI and warrant further study (McBurnette, et al., 2001). Furthermore, research on interventions for this subtype is not adequate.

The clinical interpretation of symptoms at different ages is under debate. Cuffe et al. (2001) and others (Barkley, 1998a, 1998b; Murphy and Barkley 1996a) caution that the DSM-IV age-of-onset criteria (younger than seven years) may inappropriately

exclude teens and adults with ADHD features who do not present with significant ADHD symptoms early in life. Barkley also suggests that a lower threshold for the diagnosis is appropriate for older age groups. For example, Murphy and Barkley (1996a) found that a 93rd percentile threshold for identifying older individuals (17 to 29 years of age) resulted in impairment on four of nine symptoms of inattention and five of nine hyperactive-impulsive symptoms, which is fewer symptoms than are found in children.

The erroneous impression that ADHD is primarily a middle- and upper-class Caucasian phenomenon is simply a reflection of the demographics of that portion of the population that is both aware of ADHD and has the financial resources and insurance coverage to seek diagnosis and treatment (Executive Summary, 2001). Identification is especially problematic among girls, minorities, and individuals with coexisting psychiatric disorders. Prior to DSM-IV, substantial gender disparities were reported; for example, male to female ratios of 9:1 and 6:1 in early studies (APA, 1994; Safer, et al., 1996; Weiss et al., 1985) and 3:1 in recent studies (APA, 1987; Satz-mari, et al., 1992; Zito et al., 1999; 2003). Referral patterns also influence gender distributions (Biederman et al., 1999; Nadeau, et al., 1999). In the national CPSS study of mental health service utilization, almost four-fifths (79.5 percent) of the youth with ADHD service population was composed of boys. Rate of service use was 411 per 100,000 for boys, 3.7 times higher than for girls (111 per 100,000). In other words, boys in mental health services outnumbered girls about four to one.

Selected studies report substantial rates of psychiatric comorbidity in community-based studies of children with ADHD (Wilcutt, et al., 1999), in mental health treatment populations (Biederman et al., 1995; Biederman, et al., 1991; Pliszka 1989), and in

mental health service population studies (see chapter 10 in this volume). The Multimodal Treatment Assessment (MTA) study sponsored by NIMH reported the following cooccurring conditions: 31.8 percent of children had ADHD alone, 33.5 percent had ADHD with anxiety (including 38.7 percent with simple phobia), 14.3 percent with conduct disorder, 39.9 percent with oppositional defiant disorders, 3.8 percent with affective disorder, and 10.9 percent with tic disorders (Jensen, Hinshaw, Kraemer, 2001; Jensen, Hinshaw, Swanson, 2001). However, Jensen and colleagues (1997) caution that clinic- and population-based longitudinal studies may increase the appearance of comorbidity, because persons with more severe and comorbid conditions maybe more likely to participate in ongoing studies.

Community-based studies using multiple informants, research-based assessment, and diagnostic criteria generally yield good estimates of the need for services for ADHD (Jensen et al., 1997). However, treatment studies suggest that many individuals do not receive needed services (Surgeon General's Report, 2001), particularly behavioral and psychosocial interventions.

### **Differential Access to Treatment: Age, Race, and Gender**

Many children and adolescents are not adequately treated for serious mental illnesses (Bussing, et al., 1998). Only 57 percent of at-risk boys and 20 percent of at-risk girls are referred for evaluation, despite teacher or parent concerns that "something might be wrong" (Bussing et al., 1998). Evaluation rates are also unequal for children of color; for example, only 28 percent of at-risk African-American children compared with 51 percent of Caucasian children received needed evaluations. Referral sources (i.e., parents, schools, police, and/or courts) also have an impact on whether children receive needed mental health services. Furthermore, African-American children are more likely than Caucasian children to enter the juvenile justice system rather than the mental health system, even when their symptoms are identical (Gunther-Justice and Ott, 1997). Thus, factors other than symptom severity, such as race and gender, affect referral rates (Teeter Ellison, 2002a).

Family members, friends, and/or guardians are the largest referral source (38.3 percent) for youth with ADHD in mental health facilities, according to the 1997 CPSS. The 1997 CPSS data reveal that re-

errals also came from the educational system (14.3 percent), from social service or youth agencies (12.9 percent), and from general medical programs or physicians (12 percent). Mental health providers, such as private practitioners or outpatient mental health programs, refer approximately 8.6 percent of cases. Finally, youths were also referred for mental health services from inpatient or residential care (5.4 percent) and from the juvenile justice system (2.8 percent). Thus, the points of access to treatment for youth with ADHD are varied.

## **Evidenced-Based Treatment for ADHD**

### **Treatment for Children with ADHD**

The evidence base for treatments comprises a hierarchy of information that begins with efficacy studies in volunteer research populations, which tend to be relatively brief but have high internal validity. However, generalizing to care that is delivered in treatment and to community populations is limited. Therefore, the information hierarchy extends to community-based treatment effectiveness data based on small clinic samples, ad hoc epidemiological studies, or probability samples of treated populations.

*Evidence-based Treatment in the Research Setting.* The short-term efficacy of stimulant medication is well documented to reduce the core ADHD symptoms in up to 73 to 77 percent of children (Abikoff and Gittleman, 1984; Greenhill, 1991; Spencer et al., 1996). Most critical to the efficacy literature is the NIMH-sponsored MTA described earlier. The MTA was a 14-month efficacy research study of 579 youth, ages 7 to 10 with a diagnosis of ADHD, combined type (MTA Cooperative Group, 1999a, 1999b). Children were assigned randomly to community care (CC) or to one of three MTA treatments—monthly medication management (MED-Mgt), intensive behavioral treatment (BehTx), or combined treatment (CombTx) (Jensen, et al., 2001). After careful titration, students in the MED-Mgt and Comb Tx groups were primarily medicated with methylphenidate (73.4 percent) and dextroamphetamine (10.4 percent), with fewer children on pemoline (1.4 percent), imipramine (1.0 percent), and bupropion (0.3 percent). The behavioral intervention comprised 35 sessions (8 individual and 27 group meetings), a school-based aide, teacher con-

sultations, and an intensive summer camp. CombTx included both MEDMgt and behavioral interventions.

At the end of 14 months, rates of improvement (defined as scores within a "normal" range on parent and teacher behavioral rating scales) were as follows: 68 percent for the CombTx group, 56 percent for the MEDMgt group, 34 percent for the BehTx group, and 25 percent for the CC group. In general, MEDMgt was better than BehTx for reducing ADHD symptoms, according to parent and teacher ratings of inattention and hyperactivity-impulsivity (Jensen, Hinshaw, Swanson et al., 2001). Improvements in other functional domains, including social skills, academic performance, parent-child relations, oppositional behaviors, and anxious/depressed symptoms, were slightly better for the CombTx group than for the MEDMgt group.

According to the MTA study, children with ADHD received suboptimal care in the CC group (Jensen, et al., 2001; MTA Cooperative Group, 1999a, 1999b). Even though two-thirds of the sample received stimulant medication, CC was less effective than MEDMgt, BehTx, and CombTx. So, care in the community was not carefully monitored nor as effective as the multimodal treatment (Jensen, et al., 2001) described in the MTA study.

The MTA clearly demonstrates the benefits of carefully monitored stimulant medication and behavioral interventions on core ADHD symptoms and on social and oppositional behaviors for 14 months (Jensen and the MTA Cooperative Group, 2001) and in many cases up to two years (Arnold and the MTA Cooperative Group, 2000). However, it remains unclear whether treatments exert any meaningful benefit on children's long-term outcomes (Schachar et al., 2002). Similarly, it is unclear how readily the comprehensive intervention components of the MTA can be implemented in community practice settings. Studying outcomes of care in carefully defined community populations would augment the MTA efficacy data with additional information on treatment effectiveness (and safety) in the hierarchy of scientific evidence.

Other empirically supported treatments for children with ADHD include (1) behavioral therapy and contingency management techniques (Pelham and Walschbusch, 1999; Pelham, et al., 1998); (2) a summer treatment program (STP) that includes a systematic reward/response cost program, sports skills training, 1-hour daily academic special education classroom, training in effective social skills, daily report cards, and parent training (Pelham et al., 2000); (3) parent training combined with contin-

gency management and didactic counseling to increase parent knowledge of ADHD (see Barkley, 1998a, for a review); (4) a community-based family therapy program (Barkley, 1998a); (5) the good behavior game, response-cost using the Attention Trainer (Evans, et al., 1995); (6) modification of classroom assignments and task demands (Zentall, 1993); and (7) the Irvine Paraprofessional Program (Kotkin, 1995). For a comprehensive review of interventions for youths with ADHD, see Teeter (1998) and DuPaul and Stoner (1994).

*Evidence-based Therapy in the Usual Practice Setting.* Assessing the effectiveness of treatments in community-based populations is a major challenge in understanding chronic disorders from a lifespan perspective. Epidemiological studies are one approach to address questions of effectiveness and appropriateness. Three recent studies have utilized epidemiological methods to estimate the prevalence of ADHD in community populations and to estimate the rate of stimulant medication treatment of the youths so diagnosed. Angold and colleagues (2000) found that stimulants were used to treat 75 percent of rural 9- to 16-year-olds with an unequivocal diagnosis of ADHD (full DSM-III-R criteria). However, the data raised questions about the appropriateness of stimulant treatment among the majority of stimulant-treated youths because most did not meet full DSM-III-R impairment criteria for ADHD. By contrast, data from a 1992 national epidemiological study population of 9- to 17-year-olds resulted in a far smaller proportion of rediagnosed youths—8 out of 66, or 12.5 percent—being treated with stimulants (Jensen et al., 1999). In the most recent epidemiological study, 7.1 percent of 6- to 10-year-olds during the 1997 school year in a rural North Carolina county were being treated with a stimulant (Rowland, et al., 2002). The CPSS mental health service population showed that over half (51.6 percent) of all youths with ADHD diagnoses in inpatient, outpatient, and residential treatment facilities received medication for their illness.

*Stimulant Prevalence and Trends.* Descriptive pharmacoepidemiology offers additional information that helps to characterize the extent and nature of current treatment practice. Although such information does not address questions of appropriateness or effectiveness, the data can generate hypotheses and can serve as sampling frames from which to design outcome studies to reliably assess diagnosis and to study the course of treatment effectiveness of community-based youths across the lifespan.

Table 2 summarizes current research describing stimulant prevalence estimates ranging from 1.1 to 10 percent across various community-based sources. The stimulant utilization rates per hundred youths in treatment vary according to numerous factors:

- (1) The time period captured (the point prevalence is a cross-sectional estimate whereas annual prevalence avoids seasonal variations)
- (2) Source populations, which include (a) school enrollees, (b) health-insured youths (Medicaid, Health Maintenance Organization [HMO], preferred provider organization [PPO], etc.), (c) treatment settings (medical outpatients or mental health clinic populations), (d) the study samples (i.e., total sample comprised of a self-reported information from all treatment settings or all prescribing physicians)

(3) The year of study

(4) The age of the youths (Zito et al., 2000)

Knowing how the estimate of utilization is made is critical to monitoring access and use of treatments for ADHD. Of late, the treatment population has broadened such that 10- to 14-year-olds outnumber 5- to 9-year-olds in stimulant prevalence, and the relative rate of stimulant treatment for girls has steadily increased (Shatin and Drinkard, 2002). In addition, stimulant rates vary according to the race/ethnicity of the youths with Medicaid data, showing a more than twofold greater likelihood that Caucasian youths are treated with stimulants than their non-Caucasian counterparts (Zito, et al., 1998; Zito et al., 2003). Table 3 demonstrates the consistently rising prevalence of stimulant treatment in

Table 2. Variation in U.S. community-based stimulant prevalence rates according to the specific population sources, study year, age of the youths, and whether a point or period prevalence was estimated

Time Interval <sup>1</sup>	Prevalence Estimate <sup>2</sup>	Source Population <sup>3</sup>	Study Year	Youth Age (years)	Author
One point	8–10	School	1995	≈ 7–10	LeFever et al. (1999)
One point	4.5	School	1998	≈ 5–10	Safer et al. (2000)
One point	7.1	County	1997–1998	≈ 6–10	Rowland et al. (2002)
One year	4.1	Total	1996	6–14	Olfson et al. (2002)
One year	1.1	Total	1992	< 20	Rappley et al.(1995)
One year	2.3	Medicaid	1999	≤ 18	Martin et al. (2003)
One year	9.5	Medicaid	1998	6–14	Rushton and Whitmire (2001)
One year	4.1	HMO	1997	3–17	Guevara et al. (2002)
One year	3.0	PPO/IPA	1998	6–17	Stein et al. (2001)
One year	7.5/4.2	Medicaid/HMO	1996	5–14	Zito et al. (2003)

<sup>1</sup> Time interval assessed was either a point prevalence or a period (annual) prevalence.

<sup>2</sup> Prevalence is defined as the proportion of youths with one or more prescription records for a stimulant per 100 enrolled youths.

<sup>3</sup> Source populations were counts of all youths in the appropriate age group.

the United States and Canada, a pattern that has been noted since the early 1970s (Safer, et al., 1996). Stimulant trend increases range from a modest change of 1.3-fold across a 5-year period in privately insured youths to a sevenfold change in a large northwest region of HMO enrollees.

Overall, epidemiological data illustrate substantial variations across regions, populations, and

practice sites. Additionally, data have established that primary care physicians prescribe 75 percent of the administered stimulants (Zarin, et al., 1998).

Significant need remains to clarify community practice prescribing patterns, because the substantially increased stimulant use patterns do not reveal information on their appropriateness. It is not known whether the rates signal increased access for



Table 3. The increase in stimulant prevalence from four U.S. and one Canadian population-based studies

Increase <sup>1</sup>	Prevalence Change <sup>2</sup>	Period of Change <sup>3</sup>	Youth Age (years)	Author
4.0-fold	0.5 → 2.4 survey	1987–1996	≤18	Olfson et al. 2002
3.4-fold	1.2 → 4.1 survey	1987–1996	6–14	Olfson et al. 2002
2.2-fold	4.4 → 9.5 Medicaid	1992–1998	6–14	Rushton and Whitmire 2001
3.7-fold	1.0 → 3.7 Medicaid	1987–1996	<20	Zito et al. 2003
7.0-fold	0.4 → 2.5 HMO			
4.0-fold	1.7 → 6.8 Medicaid	1987–1996	5–14	Zito et al. 2003
5.9-fold	0.7 → 4.1 HMO			
1.3-fold	2.3 → 3.0 IPA	1995–1999	<20	Shatin and Drinkard 2002
5.8-fold	0.2 → 4.1 total province	1990–1996	<20	Miller et al. 2001

<sup>1</sup> Fold-increase across the time interval measured.

<sup>2</sup> Prevalence estimates were defined as the proportion of youths with one or more prescription records for a stimulant per 100 enrolled youths from start year to end year. Separate estimates for population-based national survey, Medicaid, HMO, and IPA enrollees and Canadian provincial residents.

<sup>3</sup> Start and end years assessed during the period of change.

an underdiagnosed and undertreated condition or suggest misdiagnosis and relatively short-term episodic treatments that do not result in sustained improvement. Longitudinal studies in community settings are needed to learn more about the outcomes of stimulant therapy. There is a need for information related to (1) rates of ADHD diagnosis that represent those with substantial functional impairment; (2) longitudinal aspects of treatment, such as the extent of behavioral/psychosocial interventions, complexity of the drug regimen, time in treatment, and continuity of providers; (3) patient adherence and satisfaction patterns; and (4) the extent of improvement according to multiple domains (i.e., symptoms, functioning, side effects, and satisfaction). Moreover, the increasing recognition that some racial/ethnic groups (e.g., African Americans and Latinos) are receiving stimulant medication at a lower rate than their Caucasian counterparts (Olfson, et al., 2002; Zito et al., 2003) should be further explored.

Stimulants remain the first line medication when pharmacotherapy is warranted for ADHD; however, some new trends are worth mentioning.

*New Developments in Medication.* Long-acting stimulants are effective and are commonly prescribed to reduce the need to medicate children during school hours (Dexmethyphenidate (Focalin) for ADHD, 2001; Faraone and Biederman, 2002; Pel-

ham, et al., 2001). Also, the use of amphetamine products for the treatment of ADHD has increased (Shatin and Drinkard, 2002), and new nonstimulant medications (e.g., atomoxetine) have recently been approved and are being promoted for the treatment of ADHD symptoms.

A substantial increase in the use of medication combinations to treat youths with ADHD has been reported from 1993–94 to 1997–98, with a fivefold increase in the use of stimulants with another psychotropic medication (Bhatara, et al., 2002). An increase in the identification of comorbid disorders and a tendency to treat each with separate medications may be partly responsible for this trend. Specifically, the use of clonidine (Zito et al., 2003) and selective serotonin reuptake inhibitors (SSRIs) has grown substantially among those with a diagnosis of ADHD (Zito et al., 2002).

Emerging evidence shows that the presence of comorbid anxiety or depression has an impact on the effectiveness of stimulant medications for children with ADHD (Pliszka, 1989; Tannock, et al., 1995). Spencer and colleagues (1998) suggest that antidepressants are more effective for individuals who do not respond well to stimulants, particularly when anxiety or depression is present with ADHD. On the other hand, children with ADHD and severe aggression may deteriorate when taking antidepressants (Jensen et al., 1997). Thus, identifying co-

morbid disorders with ADHD is imperative before embarking on a trial of psychotropic medication.

*Integrating Medication with Behavioral Therapy.* In 1996, approximately 50 percent of youths with ADHD visiting community-based primary care physicians received psychotherapeutic interventions (Hoagwood, Kelleher, File, and Comer, 2000), although the extent and quality of these interventions have not been rigorously assessed. Combined therapy, when administered under research conditions as in the MTA clinical trial (MTA Cooperative Group, 1999a), had a modest improvement over medication alone (68 percent vs. 56 percent, respectively). However, the integration and successful combination of interventions deserves attention because improved results have been shown for youth with ADHD and certain comorbid disorders, such as anxiety (MTA Cooperative Group, 1999b; Jensen, et al., 2001).

## Treatment of Adults with ADHD

Treatment studies typically have focused on children 6 to 12 years of age, with far fewer studies exploring interventions for adolescents and adults (Teeter, 1998). This creates a major gap in our service delivery. Treatments for adult ADHD are typically implemented by a team of professionals, including therapists, coaches, and physicians (see Goldstein and Ellison, 2002). A comprehensive approach to treatment must be flexibly geared to the circumstances of each adult with ADHD. Treatment typically includes the following sequential stages: (1) educate the individual and his or her family about ADHD and foster a coping attitude; (2) consider prescribing and titrating medication; (3) help the individual improve life management skills for use in the workplace, home, and higher education classroom; (4) improve marital and family relationships; (5) add treatments for comorbid conditions; and (6) help the individual develop a style of coping with ADHD over the lifespan. See table 4 for a summary of promising clinical practices for adults with ADHD.

Stimulants are the medication of first choice for adults with ADHD. Stimulant medications were found to be effective in at least 15 studies with 435 adults with ADHD (Wilens, Spencer, and Biederman, 2002). In contrast to the robust 70 percent response to stimulants in children with ADHD, a much more variable positive response rate to stimulants was noted in adults, ranging from 25 to 78 percent (Wilens et al., 2002). This variability is like-

ly a function of the diagnostic criteria used to determine ADHD, highly variable doses, high rates of comorbidity, and different methods of assessing overall response. The use of antidepressants for ADHD in adults is less well studied, but appears useful for stimulant nonresponders or when mood or anxiety disorders are present.

The benefits of multimodal interventions (i.e., pharmacological and behavioral/psychological) for adults with ADHD have not been thoroughly explored. Furthermore, coaching, individual therapy, and couples therapy need to be standardized and subjected to empirical scrutiny in controlled studies to assess the utility of these approaches and to determine which interventions are effective for which problems.

The following section describes current national efforts designed to identify standards to determine the quality of mental health services provided to children, adolescents, and families with ADHD.

## Measures to Assess Treatment Quality

In response to pressures from a variety of sources (payers, payer management agents, families, advocates, and professionals), a number of national efforts are currently under way to define more clearly standards for determining the appropriateness and efficacy of mental health services. No consensus on what constitutes adequate community-based treatment outcomes for persons with ADHD currently exists, and the attempt to define quality outcome measures is a relatively new endeavor. In 1997, the Institute of Medicine (IOM), National Academy of Sciences, noted that “the research bases and the development of quality assurance and accreditation standards are far less advanced in behavioral health care than in other areas of health care” and “quality improvement methods...are still in preliminary stages for mental health” (Edmunds et al., 1997, p. 244).

During the mid- to late 1990s, significant efforts were launched in the area of adult mental health by the American College of Mental Health Administration (ACMHA) (1997), the American Managed Behavioral Healthcare Association (1995, 1998), CMHS (1996), and the National Association of State Mental Health Program Directors (NASMHPD) (Ganju and Lutterman, 1998). Although the ACMHA has sought a consensus in the mental health field, Morris and Adams (2001) suggest that these

Table 4. Summary of “promising practices” for adults with ADHD

Goals for Treatment	Strategies
Foster a coping attitude	Instill hope, optimism, and motivation to cope effectively with ADHD
Seek knowledge about and support for ADHD	Contact national organizations for information about ADHD. <ul style="list-style-type: none"> <li>• Children and Adults with ADHD (CHADD), <a href="http://www.chadd.org">www.chadd.org</a></li> <li>• Attention Deficit Disorder Association (ADDA), <a href="http://www.add.org">www.add.org</a></li> </ul>
Improve life management skills	Use coaching and behavioral, psychological interventions to set goals, overcome obstacles, address core ADHD issues (e.g., time management, organization, self-esteem)
Improve workplace functioning	Match cognitive strengths and interests for optimal functioning; strategic job placement, or change to address workplace dysfunction; career counseling; develop compensatory strategies or seek workplace accommodations
Life management skills in higher education	Transition plan from high school to college; direct, explicit instruction in setting priorities, time management, and study skills; transition plan from parental to self-direction; seek reasonable accommodations; learn self-advocacy
Improve marital and family relationships	Conjoint marital therapy to address conflicts; use cognitive, behavioral, and systems strategies; focus on realistic expectations, effective communication, damage to self-esteem, sexual dysfunction, and parenting problems
Treat comorbid disorders	Seek psychological, behavioral therapy for anxiety, mood and personality disorders, substance abuse
Coping with ADHD through the lifespan	Utilize developmental models for understanding adult ADHD; see Solder's (2002) three-stage model: Crisis of Understanding, Crisis of Identity, and Crisis of Success

Note: See Goldstein and Ellison (2002), Ratey (2002), and Robin (2002) for a discussion of promising practices for adults with ADHD.

“indicators may not sufficiently address the concerns of children, adolescents, and families.” Three national efforts to develop a consensus on quality measures for children, adolescents, and families are briefly described:

### **1. National Association of State Mental Health Program Directors**

The NASMHPD is the only systematic effort to collect and analyze performance data in the mental health field. According to the NASMHPD (2002), “state mental health agencies have the capacity and ability to implement and report on a standardized set of performance indicators.” Sixteen States are currently collecting mental health outcome measures for children: (1) satisfaction with mental health services; (2) percentage of parents involved

in treatment for their children; (3) client perception of the cultural sensitivity of their providers; (4) percentage of parents who rate service access as “good”; (5) improvement in school behavior; (8) percentage of children living in “family-like settings”; and (9) percentage of children in therapeutic foster care.

### **2. Outcomes Roundtable for Children and Families**

In 2000, with the support of CMHS, concerned professionals and families established the Outcomes Roundtable for Children and Families (Doucette and Osher, 2002). The Roundtable identified 29 measures that are in various stages of development and use. Four measures are currently given priority: (1) identification/recognition—percentage of children with a mental disorder or receiving mental

health services; (2) initiation—the percentage of clients who received services within 14 to 30 days; (3) engagement—the percentage of clients with timely and successful initiation of services who receive at least two additional behavioral health services within 30 days; and (4) access—the percentage of parents or caregivers responding that they began receiving services in a timely manner (timeliness denotes family satisfaction with services).

### 3. CMHS Children's Mental Health Program

CMHS finances children's mental health services in 61 communities throughout the Nation (Substance Abuse Mental Health Services Administration [SAMHSA], 2002) and collects uniform program evaluation data on 10 elements, some of which could be considered quality assurance measures for ADHD. CMHS evaluation data include average number of children served; percentage of referrals from non-mental health agencies; percentage of referrals from juvenile justice programs; percentage of cases reflecting cross-agency treatment and inpatient service use; percentage of cases attending school 75 percent or more of the time; percentage of cases with law enforcement contacts; family satisfaction; stability in living arrangement; and improvement in clinical outcomes.

Both the Roundtable and the CMHS efforts are leading the way for obtaining quality assurance measures for ADHD. The MTA study defined outcome measures as "normalized" or "excellent responders" on ADHD symptom rating scales, social skills, and parent-child relations (Jensen and the MTA group, 2001). Professional practice guidelines also provide a quality framework for assessing and treating ADHD.

## Clinical Practice Guidelines

Clinical practice guidelines have been developed in an effort to expand the use of best practices for treating ADHD (Committee on Quality Improvement, 2001; Greenhill, et al., 2001). The following prominent science-based publications state best practices in the assessment and treatment of ADHD in children and adolescents:

- (1) The NIMH MTA (see [www.nimh.nih.gov/events/mtaga.ctm](http://www.nimh.nih.gov/events/mtaga.ctm))
- (2) The American Academy of Child and Adolescent Psychiatry (AACAP) ADHD assess-

ment and treatment guidelines and the AACAP practice parameters for the use of stimulant medication (see [www.aacap.org](http://www.aacap.org))

- (3) The American Academy of Pediatrics (AAP) ADHD assessment and treatment guidelines (see [www.aap.org](http://www.aap.org))

In addition to practice guidelines, algorithms that map clinical choices based on evidence of medication efficacy and safety have been suggested (Vitiello, 1997). The stepwise approach is aimed at optimizing treatment and is exemplified by the study of the Texas Medicaid system (Plizska et al., 2000a, 2000b). While this approach represents a major development, its value and its impact in improving community outcomes have not yet been demonstrated.

*Medication Monitoring (time in treatment, multiple medications, and continuity of care).* The lack of longitudinal studies of community cohorts means that the duration of drug therapy, adherence patterns, and reasons youths quit treatment are not well known. Medication regimens for ADHD are becoming more complex (Zarin, et al., 1998; Zito et al., 1999) for a distinct but small pool of patients who are seen primarily in psychiatric and, to a lesser extent, primary care. Treatment complexity is associated with combinations of medications, use of non-evidence-based medications, or suboptimal dosage levels. Referral and initiation of complex regimens by one specialist and followup by another primary care provider present challenges for determining long-term treatment benefits. The continuity of care among various care providers (e.g., psychiatry, primary care, school health, and other mental health providers) and the constraints of managed care restrictions also influence treatment. One approach to improving treatment adherence is to engage families in systematic monitoring, as described below.

*Engaging Family and Youth in Monitoring Effectiveness (teacher ratings, social relations, school performance), Side Effects, and Satisfaction.* Brief systematic ratings of symptom reduction, side effects, and treatment satisfaction along with measures of functional improvement would produce a more thorough assessment protocol for individualized treatment and patient-centered, long-term goals. Behavior symptom checklists are the standard assessment tools for identifying and managing ADHD. While teacher and parent ratings are shown to differ, the importance of teacher ratings has been emphasized (Achenbach, et al., 1987). In addition, functional assessment (i.e., how the individual is

functioning in real-life settings) is necessary for adequate monitoring of treatment outcomes.

## Unanswered Questions and Opportunities to Advance Research and Practice

In recent years, effectiveness has been conceptualized as the therapeutic response under community practice conditions. By contrast, "efficacy" is a term reserved for the response to treatment under more ideal conditions, such as those described in controlled clinical trials. Yet the research infrastructure to conduct effectiveness studies for ADHD is still a work in progress. Large sample trials have been proposed as one vehicle for accomplishing this task (Vitiello, 2001). Practice-based research networks are a second approach (Zarin, et al., 1998). Internet-based reporting by families is yet another avenue that could be explored to produce longitudinal data on the success of therapy. Systematic, brief monitoring scales that are reliable and accessible to parents, teachers, and clinicians are essential for monitoring treatment.

## Summary and Implications

Symptoms and characteristics of ADHD have an impact on major life functions through the lifespan. ADHD affects approximately 5 to 7 percent of school-age children, about 80 percent of whom exhibit persistent ADHD features into adolescence and into young adulthood. Children with persistent ADHD appear to have more severe symptoms and more risk factors that increase the likelihood of comorbid disorders. Age, gender, and race factors affect referral and treatment rates, suggesting a need to be vigilant in our identification of ADHD in girls, minority groups, and older individuals.

Recent reports from the MTA study show that combining behavioral and psychosocial interventions with medication management is effective for reducing core ADHD symptoms, psychosocial problems, and oppositional behaviors in children. Although current medication patterns suggest an increase in the use of stimulants for the treatment of ADHD in children, these rates vary depending on age, gender, and minority status. Despite repeated findings that stimulant medications are effective for reducing ADHD symptoms in the short term, research on the long-term effects is crucial. Further,

we need controlled, systematic studies to determine the effectiveness of treatment approaches (family and individual therapy, coaching, school and workplace accommodations, etc.) for adults with ADHD.

Finally, there is an urgent need to develop a research infrastructure so that longitudinal studies can investigate medication outcomes that are integrated with psychosocial and behavioral interventions over the lifespan. We need to continue investigating the short-term and long-term effects of treatments for individuals with ADHD over the lifespan. Sequential, longitudinal treatment studies will be most effective for helping us determine which individuals with ADHD do well and which do not, and which treatments are most efficacious at particular stages. Determining which early interventions alone or in combination alter the developmental outcomes of individuals with ADHD is important. Polydrug treatment regimens also need to be carefully investigated because the evidence base for these combinations is inadequate. Until these things are done, many unanswered questions will remain about what works best for which individuals with ADHD.

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